



JUNE 26, 2013 MINUTES  
PATIENT CHOICE AND MEANINGFUL DISCLOSURE  
HIE WORKGROUP OF THE GOVERNING BOARD OF THE ILLINOIS  
HEALTH INFORMATION EXCHANGE AUTHORITY

The Illinois Health Information Exchange Authority (“Authority”), pursuant to notice duly given, held a meeting of the Patient Choice and Meaningful Disclosure Workgroup (“Workgroup”) at 1:30 p.m. on June 26, 2013 at the James R. Thompson Center, 100 W. Randolph St., Chicago, Illinois 60601, with video and telephone conference call capability.

| Participant Name       | Participant Representation                        |
|------------------------|---|
| Mark Pellegrino        | Illinois Health Information Exchange              |
| Marcia Matthias        | Southern Illinois Healthcare                      |
| Mark Chudzinski        | Office of Health Information Technology           |
| Shira Mendelsohn       | Office of Health Information Technology           |
| Amanda Attaway         | Illinois State Medical Society                    |
| Alan Berkelhamer       | Walgreens   |
| Brenda Bishop          | Affiliated Surgeons of Rockford                   |
| Lorie Chaiten          | ACLU (IL)   |
| Mary Dixon             | ACLU (IL)   |
| Mark Heyrman           | University of Chicago Law                         |
| Beth Koch              | Human Service Center                              |
| Brigid Leahy           | Planned Parenthood (IL)                           |
| Marvin Lindsey         | Comm. Behavioral Healthcare Assoc.                |
| Nancy Newby            | Washington County Hospital; ILHIE Authority Board |
| Laura Ashpole          | Popovits & Robinson                               |
| Rachel Godinez-Wallace | Erie Family Health Center                         |
| Laura Merten           | Advocate Health                                   |
| Marilyn Lamar          | MetroChicago HIE                                  |
| Alinea Braica          | The Association House of Chicago                  |
| Glenn Susz             | APP Design  |
| Dana Kelly             | Erie Family Health Center                         |
| Katy Yee               | DuPage County Health Dept.                        |
| Sarah Koenig           | APP Design  |
| Mary Ring              | Illinois Critical Access Hospital Assoc.          |
| Crystal VanDeventer    | LincolnLand HIE                                   |
| Lauren Wiseman         | Central Illinois Health Info. Exchange            |
| Mikki Pierce           | Atrium Advisory Services Inc.                     |
| Amy E. Cullnan         | Monahan Law Group LLC                             |
| Jodi Sassana           | MCHC MetroChicago HIE                             |
| Ayesha Haque           | AHSFHC Inc.                                       |
| Meryl Sosa             | Illinois Psychiatric Society                      |

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| Ramon Gardenhire | AIDS Foundation of Chicago              |
| Renee Popovits   | Popovits & Robinson                     |
| Joan M. Lebow    | Thompson Coburn LLP                     |
| Elissa Bassler   | Illinois Public Health Institute        |
| Danny Kopelson   | Office of Health Information Technology |
| Kathy Grossen    | Rosecrance Health Network               |
| Jeremy Kohn      | Office of Health Information Technology |
| Cari Reed        | Loyola University Health System         |

### **Call to Order, Roll Call, and Introductions: 1:36 pm**

- ✚ Committee Introduction: Mark Pellegrino (staff liaison) and Marcia Matthias (co-chair) introduced themselves to the patient consent and meaningful disclosure workgroup. Participants documented their names and contact information.
- ✚ Participant introduction: Attendees in the conference room stated their names and the organizations with which they work. Participants in Springfield stated their names and the organizations with which they work via videoconference.
- ✚ Mark Pellegrino (acting as facilitator) expressed a desire to have participants structure and organize directives and objectives during the work group meeting.
- ✚ Marcia Matthias provided an overview of workgroup topics, including, but not limited to, patient opt out, deliverables, policy and procedures, forms, regulatory language, best practices for meaningful disclosure to patients and template language for providers at the point of care for meaningful disclosure.
- ✚ Mark Pellegrino mapped out a time line (to meet every few weeks to ensure progress) and invited questions regarding the agenda. He also mentioned resources that would be made available for the workgroup online including a survey of 25 opt-out states that have done significant work to create forms and documentation, establish policies and procedures and define meaningful disclosure.
  - Question: Participant inquired about how many of the 25 opt-out states are currently operational?
  - Response: (Mark Pellegrino) Maryland has regulations that were passed by the state legislature. Some other states are further along than Illinois in implementation. It is useful to read through those state forms and best practices as well as to collect copies of policies and precedence that exist within the state of Illinois. It is important to promulgate rules at the state level that have already been implemented at the state level for the regional HIEs in Illinois (for consistency). However, ILHIE would need permission from the regionals to amalgamate this information. It would also be helpful to examine states outside of Illinois.

### **Set Agenda: 1:50 pm**



To accomplish tasks, Mark Pellegrino suggested that it might be helpful to organize into subgroups and explore ideas. Suggested groups included consumer information that should exist on an HIE website, materials that will enable providers at the point of care to provide meaningful disclosure, policy documents to submit to the Data Privacy and Security Commission for approval.

- Mark Pellegrino inquired whether any participants had any additional suggestions? One participant mentioned that it might be helpful to first make substantive decisions from one of the subgroups before moving to the next subgroup.

### **Subtopic Discussions: 1:55 pm**



**Opt-out Discussion:** The current preference is for patient opt-out to occur at the point of provider care. Thus, the provider at the point of care would provide a patient the opportunity to opt-out. The preference is that the providers take an active and primary role for the opt-out process.

- Question: (Marcia Matthias) What information will be available through the exchange? There are different data collection visions from different RIOs. It would be helpful to create a grid as to specifically which data elements are available through HIEs.
- Participant Comment: The concept of all in or out is much easier for patients to comprehend. The provider is the ideal organization to explain the opt-out.
- Participant Question: How frequent should the collection of patient opt-out at the provider point of care be done? Once per provider?
- Participant Question: Assuming we adopt a once per provider, are there triggering events that might require another dialogue? For instance, if a patient has some information they want to be kept confidential after initially deciding not to opt-out, can the patient still opt-out in the future?
- Participant Comment/Question: If the provider is charged with providing meaningful opt-out disclosure and patients only have 10-15 minutes with the physician or nurse, the opt-out may take too much time for the physician. Would physicians be unduly burdened? Who will be responsible for providing the opt-out information to the patient? Can the receptionist provide meaningful disclosure?
- Participant Suggestions: Opt-out disclosure can be in the form of a notice, a single page notice. Disclosure information becomes an issue for each provider to determine what meaningful disclosure and opt-out entail. ILHIE can recommend a policy and develop language for notices and privacy practices and forms. In terms of a workflow

at a provider facility, it is the provider who should determine whether meaningful disclosure of opt-out occurs during the registration process or with the physician. It is not for ILHIE to dictate how providers are going to manage the process. ILHIE should help providers understand the process, but leave it to the providers to determine how to convey the information to patients.

- Participant Comment: An informed consent process may need to involve the physician to be part of the process in conversation. If the patient has questions that may not be answerable by the receptionist than those questions still need to be addressed.



#### **Provider Discussion:** How do we define provider?

- Participant Question: If a patient goes to a Springfield clinic, does that mean the first doctor the patient sees is the one he must opt-out with? Would a patient not be offered an opt-out in Springfield clinic at the psychiatrist? Individuals may not think about this if the providers are in different locations and part of the same entity.
- Response: (Mark Chudzinski) The question sounds like it is grappling with frequency of collection. If a patient sees the family doctor, does that mean that he will never get the offer again at the Springfield clinic? There are several options --- opt-out can be considered perpetual until it is revoked. Another preference is that if a patient opts-out, then any participant in the HIE would know that he has opted out. It may not be necessary to repeat that process. The patient would have the opportunity to opt back in.
  - Who is the provider? How do we define it? Two ways to approach this question; the legalistic way says who is a covered entity. This might be complex because there are interdisciplinary teams, combined practices and it becomes confusing, but lawyers can sort out who is the legal entity. Who is sharing this particular EHR? That is also changing because hospitals are sharing EHRs with others.
- Participant Question/Suggestion: Is the doctor required to check the ILHIE system to see if the patient is in the system? The provider would know that the patient has opted out. Ivan said that physician wouldn't know if the patient had opted out or if they are simply not in the system. If a patient is not in the system, one set of tasks would be required and if a patient is not in the system because he has opted out, then another set of tasks would be required.
- Response: (Marcia Matthias) The law is evolving to determine if that is malpractice. There currently is no case law out there or statutes.
- Participant Suggestion: Currently you can add a diagnosis, a pop up, and ask the patient if they want to opt-out now with certain diagnosis. At our facility, we are not

disclosing certain information for teens and pregnant woman, so there could be a field put in the record system.

- Response (Marcia Matthias): Currently, we need to be open and general enough not to set the policy and procedure that will be implemented in the provider's office. It is great to generate ideas but each provider and practice is different such that what might work for one office may not necessarily translate for another office.



**Best Practices Discussion:** The federal ACO rules have said that the opt-out has to be presented once by the patients' general practitioner. This may seem strange because if a patient is only seeing a specialist, it might not happen for a long time. But this choice was made with the ACO, in the federal system under financial disclosure. Every year you get a mailing "this is a statement of your rights." This takes it away from the provider and out of the physician's workflow.

- Participant Comment: Providers do it every year differently with regards to HIPAA. Sometimes a patient will get notice every time he walks into the office. But this can be detrimental because patients also stop paying attention sometimes when they get notices weekly. Sometimes when notices are sent out too frequently, it reduces patient awareness.
- Participant Comment: It might be helpful to remind the patient that his status is opt-out. It is part of eligibility because they only register once but go through the insurance process. They know they are in the system.
- Response (Marcia Matthias): Some patients might opt-out today and then opt-back in. Patients might keep switching back and forth which could create a huge issue.
- Participant Comment: It sounds like most people are talking about a medical provider. Community healthcare behavior provider is completely different. Sometimes the first contact is with the community health facility that the patients contact. Every time you pick up a prescription you may not want to get notice.
- Participant Comment: Workers compensation: Certain information you can and cannot release to payers. It may be necessary to build some queries to not inadvertently release information to an employee unknowingly.
- Participant Comment: If your neighbor is a doctor and you don't want your neighbor to know your specific health information and he is part of this system. Can we do this on an individual provider? Who is responsible for knowing that a patient has opted in? Once I enter this system, my neighbor may have access to this system.

## Next Steps 2:30 pm



**Moving Forward:** Mark Pellegrino suggested that it might be helpful for participants to begin making themselves familiar with the "Principles and Preferences" handout. It is

not ultimately what the work product is going to be in its final version. However, having an understanding of principles and practices would be helpful for the next meeting.

- It may not be as beneficial having a group of 30-40 people talking in depth about each topic. Once participants have a chance to look through more states and see how they have resolved the issues, we may be in a better position to organize ourselves. This ILHIE Workgroup's webpage has a link to our multi-state survey of opt-out states. Today's handouts also are available on the Workgroup's webpage for everyone's ease of reference.
- Participant Question: Do you have a thought about a sequence for meetings and how to calendar?
- Response/Question: (Mark Pellegrino) Nothing less than every two weeks. We should come back in 2 weeks and break into subgroups and then reconvene as a larger group and bring everyone up to speed. This is a vast and complicated undertaking. Is 14 days a reasonable period to reconvene and become familiar with the principles and preferences document?



On July 10th we will begin the collection process from the stakeholders to contribute to the process. We appreciate information that will be released by regional HIE members and will make that available on the site. We will look into a wikipage to share information in addition to the public website.



We will reconvene on **July 10<sup>th</sup> from 10–12 pm.**